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WHEN DRINK KILLS: BIOGRAPHICAL CONSTRUCTION BY THOSE LEFT BEHIND

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Drinking Dilemmas Conference
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INTRODUCTION/AIMS OF PRESENTATION

- To introduce the experiences of a hidden population of family members and individuals bereaved by an alcohol-related death.
- Using data from 11 interviews conducted as part of a larger study to explore and illustrate:
 - How this group makes sense of and lives with the memory of a life and a death defined by alcohol.
 - How this group's experiences may contribute to the debate around 'drinking dilemmas'.



BRINGING TOGETHER TWO FIELDS OF STUDY

We know about:

- Bereavement generally and in relation to some problematic or 'bad' deaths, e.g. the death of a child, stillbirth, suicide, homicide, AIDS.
- Impact on families of living with a relative's alcohol or drug misuse, plus estimates of the numbers affected.

We know very little about:

- Impact on those families when the relative dies as a result of their drug- or alcohol misuse - though statistical recording of such deaths reveals their prevalence.
- Almost no UK or international research in this area.




THEORIES OF GRIEF

- Grief theorised as major psycho-social transition (Parkes, 1988) in face of death's shattering impact on one's sense of meaning, identity and continuity of being
- Restoring sense of identity and thread of continuity found to be dependent on:
 - sharing with /talking to sympathetic others about the deceased person, i.e. **social support**.
 - Preserving and finding comfort in the deceased person's memory and/or continuing presence, i.e. **memory-making** and **continuing bonds**.


Parkes, C. (1988). Bereavement as a psycho-social transition: Processes of adaption to change, *Journal of Social Issues* 44(3) 53-65



GOOD AND BAD DEATHS


- Experience of grief also found to reflect extent to which death considered good or bad:
 - Good deaths: expected, manageable, e.g. deaths in old age.
 - Bad deaths: outside bounds of normal expectations and acceptability, e.g. premature deaths of young people
 - Some bad deaths, particularly drug or alcohol-related, attract stigma rather than sympathy, due to being perceived as:
 - Self-inflicted, preventable - outraging assumptions about sanctity of life.
 - Linked to deviant life style, i.e. bad life as well as bad death.
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OVERVIEW OF STUDY

- ESRC funded, 3 year study of family members and others affected by the alcohol- or drug-related death of a loved one.
 - Across 2 sites – South West England and Scotland - and in 2 phases
 - Bereaved family member on project team.
 - Phase 1: 100 in-depth semi-structured interviews with bereaved individuals and some couples - 96 completed and final 4 scheduled.
 - Analysis (using Nvivo) ongoing.
 - Phase 2: Developing practice guidelines informed by interview findings, with the help of focus groups and working group.
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Participant	Deceased	R'ship of P to D	Cause of death
F 49	F 23	gay partner	Sudden adult death syndrome
F 37	F 63	daughter	Alcoholic hepatitis
F 24	M 45	niece	Heart attack
F 33	M 51	daughter	Accidental death (fire)
F 54	M 54	ex-wife	Death by ligature
M 24	M 49	son	Multiple organ failure
M 31	M56	son	Heart failure due to long-term alcohol abuse
F 75	M36	mother	Pneumonia and liver failure
F 65	M39	daughter	Unclear
F 30	F 40	daughter	Drug O/D with alcohol
F 57	M 20	Mother	Cardiac arrest brought on by alcohol

MOURNING A DRUG OR ALCOHOL-RELATED DEATH

- Our emerging findings suggest that this type of death can be difficult to grieve due to 4 factors/dilemmas:
 1. **Life:** pressures of living and coping with the person's drinking while they were alive.
 2. **Death:** circumstances and what happened after the death.
 3. **Stigma (actual and perceived):** society may stigmatise the death and blame/pathologise the family, devaluing their grief and depriving them of social support.
 4. **Memory:** remembering (formally and informally), a life that may be considered unfulfilled or wasted. Dilemma around remembering the deceased as a 'whole person' or 'an addict/alcoholic'.
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MOURNING A DRUG OR ALCOHOL-RELATED DEATH

- How participants negotiated these dilemmas can be influenced by:
 - Diversity of the sample.
 - Creative responses to negative and dissonant cultural norms.
 - Response of others – families, friends, professionals.
 - How meaning may be found through gaining further understanding of alcohol misuse/addiction, and of grief and bereavement.



1. LIVING WITH ALCOHOL MISUSE

- Impact of the death influenced by the bereaved (and others) experience of living with substance misuse before death.
 - Alcohol misuse often long-standing & accompanied by other serious problems.
 - Some participants affected by substance misuse of more than one person – some experienced more than one death of this kind.
 - Some participants themselves in treatment/recovery because of their own substance misuse.
- Experiences after death align with the theoretical 'stress-strain-coping-support' model of how families may be affected.
- Death may have been expected, sometimes there was a sense that the person had 'died' long ago.
- Differences of opinion within families/networks can bring conflict and tension post-death and impact upon support.



THE DEATH MAY BE EXPECTED


“....we'd never ever expected him to die ever. We used to say it and we used to say, 'Dad if you don't stop drinking you're going to kill yourself'.....but we never believed it” (son)

“.....when [my son] didn't get back to me I knew the police would be coming to the door. So what I imagined in my mind a thousand times, it's exactly the way it happened, the only difference was I knew they were coming” (mother)

“I believe spiritually that he died a long time before his body did” (daughter)




UNDERSTANDING ALCOHOL MISUSE

- Range of understanding.
 - Particular terminology when describing their loved one – words like alcoholic & addict dominated.
 - Strive to learn/find out more about addiction after the death to help them understand their loved ones life and death.
 - Understanding life to understand death.
 - ‘Disease model’ of addiction seemed to be a particular comfort/help to some – their loved one had a illness – removes responsibility from deceased & participant.
 - Broader understanding may help some feel less to blame and that there was more they could have done.
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UNDERSTANDING ALCOHOL MISUSE

“I was always trying to be supportive of him, because nobody grows up to be an alcoholic do they? Nobody wants to be that way....I didn't care that he was an alcoholic. He was still my uncle and I just wanted to help him” (niece)


“....addiction is cruel, it's very cruel and it's more cruel for the ones left behind.....I don't think it [addiction] makes it special....I think that the....for the families is that they blame themselves” (female partner)



PRESENCE OF ALCOHOL (AND DRUGS) IN OTHER WAYS

- Participants who themselves have/had alcohol problems – in treatment/recovery.
 - Association between their use and the death – and their treatment/recovery.
 - Influences experience/impact/understanding of the death.
- Important role to play in other ways, and for others who do not have such problems.
 - Coping/escapism.
 - Presence of alcohol at funerals.
 - Remembering.

“....he loves St Patrick's Day and I usually take a beer with me. If it is St Patrick's Day I will pour it on the grave. Because I know he's an alcoholic, but at the end of the day that was his thing. Paddy's Day was a good knees-up and why shouldn't he after he's died” (niece)



2. THE DEATH

- How participants talked about the death reflected norms around where, when and how one should die, e.g. at home, with dignity, in the company of close others.
- For some cases this ideal was partially achieved.
- For others the experience was far removed from the ideal, to include dying alone or away from home, in the presence of professionals, without privacy or dignity.
- Impact in terms of e.g. saying goodbye (including seeing the body, the funeral).
- Relief (for participant and deceased) – but dilemma associated with this (e.g. guilt).



DIGNIFIED DEATHS

“she ended up in ... hospital and she was on a ward, full of people, confused, didn’t want to be there, kept trying to get out of bed, was driving the nurses crazy ... and she had a catheter in and ... she was very confused.. and every time we were there everybody just stared at us, it was horrendous and I kept saying this is just not dignified, this is awful... This is so undignified and my mum was a lady of, she like.. you know she was very private, liked her dignity and I just thought in her conscious state she would be mortified by this...” (daughter)



SAYING GOODBYE

“I had so much mixed feelings....the more I kept looking at her the more angry I was getting....and I thought what's the point you know she is going to die, there is no point in being angry and shouting you know. But when I looked at her I just, a lot of [bad] memories were coming back.....but no I just took her hand and I didn't want that, I had said the goodbye I had wanted to give her”
(daughter)




DEATH MAY BE A RELIEF

“...I know it's an unusual thing to say but I prefer it that he's dead you know, it's been so much more peaceful since he's died, just to not have to witness someone's profound suffering like that....it feels like he's at peace, that's how it feels now” (Son)

“sometimes I do think to myself, maybe it was better for him to pass away because of the pain he was just going through. You know every day was a battle with him. His addiction was just too powerful. It was just way too powerful for him.....And I just sometimes think maybe now he's at peace and he's not at war anymore, maybe he's a lot happier” (niece)

“So for me when she first died it was a relief that that was over and that.....it is difficult because you feel guilty for feeling like that.....you think it's wrong to have feelings like that and therefore you feel that perhaps you don't have right to grieve and be so upset.....it took me a while to realise that I had the right to be upset” (daughter)



3. STIGMATISED DEATHS AND DEVALUED GRIEF

- Mourners having to negotiate cultural stereotypes of an alcoholic life-style (exacerbated by media reporting) in which family often implicated, raising dilemmas associated with
 - Lack of support and understanding making it difficult to share experiences with others (fear of conflict, tension, differences of opinion both within as well as beyond family).
 - Self-stigma and perceived responses of others.
 - Insensitive response of professionals e.g. police; delays with inquests.
 - Silence about presence of alcohol in the death, i.e. not discussed, acknowledged as the cause of death.
 - Challenging stereotypes/black and white perceptions - the person was more than their addiction.



STIGMA AND LACK OF SUPPORT

“If somebody had offered me grief counselling....if there was you know, if it wasn't such a stigma. I don't know why it is but it just seems like this society is a 'get over it' type of society. If there was more help out there available for people who lose people, you would avoid so much pain and hurt”
(daughter)

“I noticed how lost the family were after this death. And we just didn't have any support” (niece).



ALCOHOL MAY BE IGNORED

“I remember at the funeral I wanted any proceeds to go to Nacoa [National Association for the Children of Alcoholics]. I didn't do work for them at the time but I wanted, my brother-in-law didn't want the funeral to have any mention of alcohol. So I thought, this is what killed him but we're not to mention it” (Ex-wife)



CHALLENGING STEREOTYPES

“I think I was really conscious of the fact that I didn't want anyone to think just because he was an alcoholic and just because he died young doesn't make him a bad dad, he was a fantastic father, he really was....and I wanted people [at the funeral] to know how special he was to us” (son)

“I won't have anyone speak ill of my family or my mum or anything....she is not here.....I am very protective of my family, even my mother despite what she has done.....it's no reason for anybody to speak ill of her” (daughter)



4. REMEMBERING A LIFE DEFINED BY ALCOHOL

- Cherishing fond memories considered key to finding continuity and meaning in the loss, so remembering a life defined by alcohol may pose dilemmas around
 - Coping with difficult memories, including the sense of waste of life
 - Finding comfort through a continuing bond with the deceased.
 - Acknowledging anything good that may come out of the bad



NEGOTIATING DIFFICULT MEMORIES

“Yes I do believe that she’s like in heaven having a lovely time, she’s fine, she’s happy, she’s peaceful ... Do I imagine her with a drink or without a drink, or would I rather have her back with all her problems ...you wish them to all go away - but then you just think well I’d like to have her back with that just as much as without, so no I do yes, I don’t, you know I obviously have an image of her lying on the floor in her own faeces, alcoholic stupor you know and I have that image but it’s not the one that I carry around with me you know. ”
(daughter)

“God bless her she was a good woman. Apart from her drink problem, she loved her kids and she was a good mum.....I do try to think a lot of the good times. But there wasn’t a lot of good times you know” (daughter)



A WASTE OF LIFE

“I felt really sad that what a waste of life you know, I felt really really yes, really sad for him. I thought to end like that so young, because he spent a large part of his life being depressed”
(son)

“I miss the person that he would have been you know or the person that I think he would have been you know” (mother)

“.....I always had this hope.....[but] when she died I lost my hope and that was the saddest thing for me that there was no hope of it ever getting better” (daughter)



A CONTINUING BOND

“Well, it started with our first Christmas without [him]. I decided I would write him a Christmas card... and I dated it and sealed it and put it in a tin. And then just after Christmas with what would have been his 24th birthday, I sent him a birthday card and put it in the tin. And then when it got to the anniversary, the first anniversary, I wrote him a letter. And in the letter I told him about things that had happened since he died.So this tin is now absolutely full of letters that I've written to [him] and I'm still writing to him. And that's the only way that I can kind of hold it together” (mother)

“....he's alive all the time. He's alive when I get up in the morning. I think of him every single day. There's not a day that doesn't go by that I can ever think I haven't thought of him” (niece)

ACKNOWLEDGING THE GOOD IN THE BAD

“But for me I wanted to understand why she drank I think. And I don’t have the answer to that but I think I’ve tried to understand a bit more about my family dynamic and why things are as they are, tried to piece together some of the things that perhaps weren’t quite as they seemed...and learning.. I suppose going by how it’s affected me in positive ways as well as negative ways... I definitely, you know would I change it? I would like some of the pain to have gone away but I do think the relationship I have with my mum has made me who I am and from that I have a lot of empathy and a lot of determination and it has enabled me to achieve things in my life that I may not have done otherwise” (daughter)



CONCLUDING THOUGHTS

- This is a group who face several complex and distressing dilemmas.
- Extending knowledge about how people can be affected by the substance misuse of a loved one.
- Contributing to gaps in understanding sub-groups of the bereaved, and theories of grief & bereavement.
- Our findings suggest that there are similarities with other types of death, but that there may be factors which are unique to this type of death.
- Our thoughts are preliminary & exploratory, and our findings will evolve as we continue to analyse.
- This is a group lacking in support (before and after death) and we hope that the lived experiences of our 100 participants, and how they will inform phase 2 of our project, will raise awareness resulting in greater attention within policy & practice.



MORE INFO ON OUR PROJECT

<http://www.bath.ac.uk/cdas/research/understanding-those-bereaved-through-substance-misuse/>

The rest of the Project Team:

- Tony Walter, James Earl-Fraser (University of Bath).
- Linda Bauld, Jennifer McKell/Allison Ford, Carole-Anne Greenan (University of Stirling).
- Joan Hollywood, Gordon Hay, Richard Velleman (Consultants).



WHY OUR STUDY IS IMPORTANT

“...bereavement is a difficult thing for people to, or death is a difficult thing for people to deal with anyway, they react weirdly to it. But the fact that it is death through an addiction I think emphasises that” (daughter)

“I just think if me taking part in this, if that's going to help a family who loses somebody.....It doesn't matter who if they're so deeply impacted by it. If this research means that they're going to be fully supported and they don't have to feel alone, then that's just going to be amazing” (niece)

“....one of the things that sticks in my mind about my mum's death is the undignified way she died and how I should have had more of a voice to have done something about that.....to me if I can talk about some of that that maybe produces some guidelines that makes something different for somebody else, that would be a really positive thing to have done” (daughter)

